



## ISOU Patient Engagement Subgroup - Terms of Reference

### Background

There are a wide number of co-dependencies within the OUG report recommendations and cross cutting themes. This makes implementation complex, particularly when considering the wider context of other activity already underway.

To aid implementation, fixed term ISOU subgroups are being established to provide a strategic steer on some of the more complex areas of work. Subgroups will focus on specific areas of implementation activity, bringing together knowledge and expertise from the organ donation and transplantation community to commence new work and/or provide assurance and reassurance on the operational delivery of the OUG recommendations.

Patient engagement is a critical component of ISOU's work. In line with the ethos of the OUG report – to place the patient at the heart of the transplant service – the Patient Engagement (PE) subgroup will ensure patients' views are a key consideration in the implementation of the OUG recommendations. This will ensure ISOU and the organisations involved in delivering the OUG recommendations demonstrate continued commitment to patient engagement throughout the implementation period and beyond.

### Remit

The Patient Engagement subgroup will:

- Provide advice on the best practice and approach for ISOU subgroups and associated implementation activity in patient engagement.
- Provide assurance and reassurance to ISOU<sup>1</sup> on the actions being taken to deliver the OUG recommendations.
- For those recommendations that are patient focussed – advise on implementation approach, having consideration of the context and other relevant examples and approaches from other areas.
- For those recommendations that are not patient focussed – advise on the best practice with patient engagement approach.

The recommendations and implementing actions within scope of the PE subgroup are detailed below. These have been split into short/immediate term and longer-term groups, reflecting that some recommendations/implementing actions have been

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<sup>1</sup> And subsequently Ministers, via the ISOU reporting processes

prioritised to be delivered in the near-term future, while others will be delivered on a longer timescale.

The PE subgroup will consider: adult and paediatric services: engagement with families and carers, patients with disabilities and their carers.

The PE subgroup's assurance and reassurance will follow a three-step process:

- Step 1 – assurance of the activities and actions delivery organisations are taking to make progress on the relevant recommendations
- Step 2 – reassurance that wider rollout of these actions and activities across the system is effectively reaching/engaging all patient groups
- Step 3 – longer-term assurance/reassurance in the form of evaluating all activities to provide a strategic view on the effectiveness of system-wide changes (i.e. making a strategic assessment of whether patient engagement has been placed at the heart of the transplant service, based on all the evidence gathered across all short and longer-term recommendations/implementing actions)

### Out of Scope

The PE Subgroup is not a discussion group to raise additional concerns that are outside the ISOU remit.

It is not to provide the implementation work itself, but to provide advice and best practice on patient engagement processes to inform:

- the local/ regional/ national implementation activity.
- implementation of those recommendations with a specific patient focus (i.e. recs 1 & 2)

Responsibility for wider engagement with patient and clinical teams regarding updates on ISOU activity lies with the Stakeholder Forum. The PE Co-Chairs will attend the Forum as appropriate to provide updates on progress, but will not be responsible for disseminating messages regarding ISOU work.

### **Membership**

The ISOU Co-Chairs will work with the PE subgroup Co-Chairs to identify and invite individuals with the relevant expertise to contribute to the group.

Membership will include representatives from diverse patient populations (i.e. age, gender, ethnicity, geographical location, organ type, stage of the care pathway etc.) as well as representatives from donor/family groups.

Membership will also include expertise in communications and approaches to engage wider patient populations, to support the provision of accessible and useful updates on implementation work.

The PE Subgroup will include knowledge of:

- Patient engagement in healthcare policy, service design and service delivery.
- Trust-level expert in patient engagement
- Trust-level expert in patient equity and access
- NHSBT Transplant Patient Chairs – or their nominated representative
- Expertise in engagement in healthcare setting with minority communities
- PROMs and PREMs for transplant patients
- Communication with patients and carers with disabilities and paediatric patients.

### **Links to the Stakeholder Forum**

An ISOU Stakeholder Forum has been established to provide an interactive forum for key stakeholders to express their views and feed into the implementation of the OUG recommendations.

While the Stakeholder Forum will include engagement with patient communities, its membership will have a significantly broader scope than the PE subgroup. The Stakeholder Forum will include clinical communities, commissioners of services and professional bodies/groups, all of which are outside the scope of the PE subgroup.

The broader membership of the Stakeholder Forum also ensures it will have a broader scope of work than the PE subgroup. All the OUG recommendations will be within scope of the Stakeholder Forum, whereas the PE subgroup is being established to focus only on those OUG recommendations that have a specific patient focus (as detailed above).

Where there is crossover between the two groups from a patient perspective, the ISOU Secretariat and ISOU Co-Chairs will work alongside the Co-Chairs of the PE subgroup and Stakeholder Forum to ensure the groups work collaboratively and avoid any duplication.